# NIDCD Administrative Supplements for Data and/or Resource Sharing

The National Institute on Deafness and Other Communication Disorders (NIDCD) announces the availability of a limited number of administrative supplements to existing NIDCD-supported R01, P30, and P50 grants in the areas of hearing, balance, smell, taste, voice, speech and language. The purpose of the supplement is to support efforts to promote data and/or other resource sharing.

## History:

The National Institutes of Health (NIH) is encouraging all grant applicants to include a plan for sharing data and/or resources. Sharing data and resources promotes many goals of the NIH's research endeavor and is particularly important for unique data or resources that cannot be readily replicated. Data and resource sharing allows scientists to expedite the translation of research results into knowledge, products, and procedures to improve human health; reinforces open scientific inquiry, encourages diversity of analysis and opinion, promotes new research, makes possible the testing of new or alternative hypotheses and methods of analysis, supports studies on data collection methods and measurement, facilitates the education of new researchers, enables the exploration of topics not envisioned by the initial investigators, and permits the creation of new data sets when data from multiple sources are combined. By avoiding the duplication of expensive data and/or resource collection activities, the NIH is able to support more research than it could if similar data and/or resources had to be produced *de novo* by each research program.

#### Examples/Further Description:

Scientists working in many different areas are already sharing their data or unique resources through a variety of mechanisms. Some studies, such as small laboratory-based projects, make raw data available in publications. These studies generally are based on small numbers of laboratory animals, specimens, or clinical subjects. Publishing the raw data constitutes an acceptable mechanism for sharing data, provided that privacy of human subjects is protected. However, raw data from large studies are not amenable to sharing through publication. Such studies can make data available through data archives or enclaves. For example, gene mapping, anatomical and survey data are available from data archives or repositories, some with sophisticated Web interfaces. Specific animal models or enzymes, antibodies, or other reagents that are unique are examples of resources that might be shared. Data from human subjects present special concerns regarding data sharing. The rights and privacy of individuals who participate in NIH-sponsored research must be protected at all times, and patentable and other proprietary data should also be protected.

All data and resources should be considered for sharing. Data or resources that constitute "unique resources" especially should be shared unless there is a strong reason not to. Such data or resources are difficult if not impossible to replicate because of cost (e.g., large national longitudinal surveys), special circumstances (e.g., health effects associated with a natural disaster), or rare population (e.g., a family with a rare genetic disorder). Less likely candidates for sharing are data from small studies involving research procedures that are easily replicated or data from human subjects that might identify them. The following web site has more information about ways to share data and/or resources:

http://grants1.nih.gov/grants/policy/data\_sharing/data\_sharing\_guidance.htm#methods.

Examples of types of supplements for data and/or resource sharing include, but are not limited to:

 Support of the cost of breeding, rearing, genotyping and shipping genetically modified animal models

- Distribution of software tools and source code available to gather or analyze neurophysiology data, such as to create regional topographical maps of specific brain areas
- Costs of sharing the design and construction details of special purpose hardware or electronic circuit resources
- Costs associated with obtaining DNA from well-phenotyped pedigrees and populationderived samples; linkage and association genotyping data from large data sets (including haplotype data); expression data (e.g., microarray, proteomics) obtained from human or non-human tissues; genome context expression data
- Making epidemiological information related to disorders of hearing, balance, smell, taste, voice, speech and language available to other researchers
- Making available large data bases of voice, speech and/or language samples of normal acquisition or data from specific or unique populations
- Providing neuroimaging data associated with specific abilities/deficits in hearing, balance, smell, taste, voice, speech or language to the research community
- Allowing other researchers access to databases of acoustic or kinematic information associated with normal and/or disordered voice, speech or language function

## Eligibility:

The NIDCD will consider requests of only one application per Principal Investigator (PI), regardless of how many NIDCD-funded grants/subprojects/cores are headed by that PI. Under compelling circumstances, and with clear justification, more than one application may be received from a P50 or P30 grant (i.e., individual subprojects on P50s and individual cores on these grants are eligible for a supplement, but the rule of only one supplement across all mechanisms, per PI, still applies). The costs associated with data and/or resource sharing will vary substantially depending on the type of data/resources to be shared, as well as the methods chosen for sharing data and/or resources. The NIDCD will support up to \$50,000 TOTAL costs as a one-time award to support efforts to promote sharing of data and/or resources from a research or research and development program. Supplements are not renewable, and any consortium costs and/or subcontract costs (if requested) must be included in these costs. Only parent grants/contracts funded through September 30, 2004 are eligible.

### Application Instructions:

The request for the administrative supplement must be postmarked by **June 1**, **2003**, with an earliest possible award date of **August 15**, **2003**. The NIDCD expects to make 25-30 awards in Fiscal year 2003, based on the merits of the applications, as well as the availability of funds. Supplement requests should contain enough detail to allow the NIDCD to determine the merit of the proposed plans for data and/or resource sharing, as well as the need for additional funds. Though it is preferred that the parent grant have at least 2 years of active funds remaining, applications funded through September 30, 2004 will be accepted if properly justified.

The request for the supplemental award MUST include the following:

- A completed face page, including appropriate signatures, from <u>Grant Application Form PHS 398</u> (Updated 6/02). Include the title and number of the parent grant on line 1 and enter 'Data and/or Resource Sharing Administrative Supplement' on line 2.
- 2. A description (maximum 5 pages) prepared by the principal investigator of the parent grant that includes:
  - Brief summary of abstract and specific aims of parent grant (no more than 1 page).
  - Detailed description of proposed plans to promote data and/or resource sharing and how the plans relate to the aims of the parent grant. The method selected will depend on several factors, including, but not limited to, the sensitivity of the

- data, the size and complexity of the dataset, the type of resource and the volume of requests anticipated.
- Description of the likely impact of sharing data and/or resources to the targeted audience(s) (e.g., how will the planned efforts facilitate achieving specific solutions to scientific or clinical problems?)
- Description of how the goals of the proposed plans for data and/or resource sharing will be accomplished within the timeframe of the parent grant.
- 3. An itemized proposed budget on the budget pages from Grant Application Form PHS
- 4. Inclusion of plans for safeguarding the privacy of participants, and protecting confidential and proprietary data, where appropriate.
- 5. Should the proposed efforts require animal involvement different from that of the parent grant, approving documentation by <u>Institutional Animal Care and Use Committee</u> (IACUC) must be provided.
- 6. A letter indicating approval and commitment of resources and effort of the proposed activity from the applicant's institution.
- 7. There is a post-award requirement of a one-page summary of results generated by the supplement to be included with the next progress report to the NIDCD.

The following website should provide further information that will be useful in preparing your application: http://grants1.nih.gov/grants/policy/data\_sharing/index.htm.

One original and 2 copies of the application should be mailed to:

Lynn E. Luethke, Ph.D.
NIDCD/NIH
6120 Executive Blvd, 400-C
Rockville, MD 20852 (if using courier services – e.g., Fed X, UPS)

Or:

Lynn E. Luethke, Ph.D.
NIDCD/NIH
6120 Executive Blvd – MSC 7180
Rockville, MD 20852-7180 (if using regular U.S. Postal Mail services)

Applications must be postmarked by **June 1, 2003**. The request SHOULD NOT be submitted to the NIH Center for Scientific Review (CSR). Prior to submission, applicants are strongly encouraged to discuss the specific details and reasoning for supplement requests with Lynn Luethke either by phone (301-402-3458) or email: lynn\_luethke@nih.gov.

Requests for supplements will be reviewed administratively for eligibility, relevance to the NIDCD mission, need for the data/resources, likely impact to scientific and clinical research endeavors, and merits of the proposed plan for sharing data.